International Society for Mannosidosis and Related Diseases



The International Advocate for Glycoprotein Diseases a 501(c)(3) not-for-profit organization, FEIN 52-2164838 www.ismrd.org | info@ismrd.org | P.O. Box 683, Turnersville, NJ 08012, USA

Achievements Through the Years

1999 ISMRD was established

2000 Website launched

2003 1st Scientific/Family conference held in Washington D.C.

2004 Penguin Cafe was launched

2005 "Crossing Oceans for a Cure" workshop and fundraiser held in Michigan bringing together the largest group of ML families ever

2006 ISMRD partnered with the Greenwood Genetic Centre to develop a Natural History Study for our 9 diseases

2007 2nd Scientific/Family Conference held in Michigan

2008 Consensus development meeting bone disease in Mucolipidosis held in New Zealand; AMP scholarship gained to extend the Natural History study to New Zealand and Australian patients

2009 Successful support of \$250,000 application to NIH for Natural History study continuation

2011 ISMRD wins Patient Advocate Leaders Award for Innovation from Genzyme

2012 3rd Scientific/Family Conference held in Charleston, South Carolina

2013 Chase Community Giving grants \$10,000 to ISMRD

2015 4th Scientific/Family Conference held in St Louis, Missouri

2017 5th Scientific/Family Conference held in Rome, Italy; Vatican letter of blessing

2019 6th Scientific/Family Conference held in Atlanta, Georgia

2022 Assisted with PGT-M testing for Fucosidosis families in the UK

2023 Assisted with PGT-M testing for Sialidosis families in the UK; ISMRD-Sponsored ongoing research into the long-term effects of Bone Marrow Transplant on Alpha-Mannosidosis

2024 ISMRD-Sponsored Feline Mucolipidosis completed research projects: Gene Therapy Research in Mucolipidosis: *To Evaluate AAV Gene Therapy in the Feline Model of ML II* and <u>GNPTAB-related Disorders</u>; ISMRD becomes founding member of the Global LSD Collaborative; ISMRD celebrates 25 years